



Welcome all,

Well... what can I say about how this year is going... It certainly took a turn for the worse just as the last newsletter went into the post. It's hard to come to terms with how everything can change so hugely in such a short space of time

I've been finding it fascinating to see how this country has adapted to cater for the effects of the virus. Home working and support for home schooling is now available to most. Theatre releases and music concerts are available to those at home. How many of our members have been told in the past that adaptations couldn't have been made for their illness? It's also been interesting to see how fit and healthy people cope with being confined to their house – usually with great difficulty and frustration. Will the ME and fibro sceptics still think that we are faking it? - to have what they might have seen before as a 'grand old life'? This is not a lifestyle that anyone wants.

More and more we see stories in the press about people who have had Covid-19 and haven't recovered from it. As I feared a small, but sizable percentage, are coming down with persistent ME-like symptoms. This shouldn't be a surprise as previous corona virus outbreaks (SARS and MERS) along with other viral outbreaks have led to the same thing. I am hoping that these people will be treated more sympathetically than we have been and that it will lead to greater understanding and more research which could eventually benefit us. In the meantime, we will need to educate people about ME and Post-Viral Fatigue Syndrome and the importance of allowing the body time to recover. I'm sure we all have experience of what pushing too hard, too soon, when we first fell ill has done for our condition. It is vital that this message gets out to give those who don't rebound the best chance of avoiding a long-term chronic illness.

The irony that the NHS Covid-19 hospitals in England were named after Florence Nightingale (on her 200th birthday) didn't escape me. She is thought to have suffered with ME or fibromyalgia for the latter part of her life.

Please take care, stay safe from the Corona virus and keep in touch with us.

Craig Woods

Online Get-Togethers

Every Thursday 2pm – 3pm on Zoom.

Guests will include:

25th June: Des Quinn, Chair of FMAUK

2nd July: Dr Charles Shepherd, Medical Advisor to ME Association, ME advocate and sufferer.

23rd July: Emma Harper MSP

Look out for updates and other guests on our Facebook page or website meetings page.

Contact us:

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Registered Charity No. SC030641





Our Online Meetings

It'll be no surprise that we can't meet up in person for the foreseeable future. In the meantime, we are holding online meetings using Zoom. It's a platform which allows effective video conferencing, and much of UK business, charity and even families and friends have turned to it. The government has been using it for cabinet and committee meetings and it was used when MPs couldn't attend parliament. The Network has subscribed and we've found it very effective. Video and sound are clear and it's simple to use.

Some tips:

- use the device with the largest screen you've got to see as many participants as possible on 'gallery view'
- use 'speaker view' on smaller devices
- Mute your microphone when not speaking - on laptops and pc press space bar to talk
- Raise a hand or indicate some way that you want to speak

It's free to download from www.zoom.us and you won't need to create an account. Follow the link that we publish on our Facebook page, add the password, and click 'connect to computer audio'. For first time use you will need to give permission for Zoom to access camera and microphone. Please do join with camera enabled. Don't feel self-conscious. Being on video helps to manage the meeting, helping to see when someone wants to speak, and helps us judge when everyone is tiring.

Dr Purdie, former GP at Castle Douglas, Clinical Lead for ME in D&G, Medical Advisor to Action for ME, has been joining us when he can. We've also held a meeting where we asked Phil Sizer from the Pain Association to talk us through what they offer (more about that later). We hope to add speakers and people of interest in the future, so keep an eye on our Facebook page and website for more information.

The meetings happen every Thursday from 2pm.

Meeting ID: 302-429-868

Message us for the passcode, check your email or log on to our [Facebook page events section](#).

We won't change the Meeting ID or passcode unless we have to so it should work for each meeting. If we do change it, we will notify you via Facebook or email, so please check your contact details are up to date.

Dr Charles Shepherd, Thursday 2nd July, 1:50pm

I'm very excited that Dr Charles Shepherd, a long-time hero of mine will join us on Zoom. He was a GP when his ME was triggered by a case of Chicken Pox which he didn't recover from. He is a campaigner, advocate and Medical Director of the ME Association. He has written Living With ME, a must-have book for everyone with ME, and with Dr Abhjit Chaudhuri, the 'Purple Book' guide for health professionals.

He will give us a quick 15-minute summary of all the current 'hot topics'



- COVID19 and ME/CFS and the huge fundraising problems that this has created for the charity sector (we have only had to cut one staff post so far)
- FORWARD ME Group
- NICE guideline
- Parliamentary activity - APPG on ME report
- Research - including the Biobank and the MRC funding application for the GWAS/genetic fingerprint study

He will then take some questions on anything that people want to raise...

He joins us a day before the latest meeting on the revisions to the, currently awful, NICE Guidelines.

Emma Harper MSP, Thursday 23rd July, 2pm

Emma is an SNP list MSP for the region. She is also a registered nurse and has been helping out the NHS at D&G Royal Infirmary part time during the pandemic. She has agreed to join us to talk with us and hear our concerns and our problems.

Invitations have also gone out to our other MSPs locally across the political parties. They would normally be consulting with their constituents locally during the summer recess, so I fully expect they will be happy to join us. This is a great opportunity for us to lobby for the better care we need. Look out online and in your email for updates.

Facebook Messenger Rooms

Facebook, not wanting to miss out, have launched a competitor to Zoom. We've tried it but found it less successful for larger groups, but easier to use for a small impromptu discussion within the Facebook page. I've added it to the Network's group page so now any page member can click on 'Rooms' at the top of our page, it will send a Facebook notification to anyone who has used it before and someone may join you for a video chat. It's another nice way to keep connected in these socially distant times.

Facebook

There is also now a second Facebook page, connected to our main page. It is the place for light-hearted, non-illness related banter, jokes (some a bit more risqué), TV and Netflix recommendations and more. It's called the DGMEFM Social Café. Anyone who is a member of the main page can join with no approval needed. Membership is kept to only people within the main group, so only your fellow sufferers and page members will see anything posted within it.

Our main Facebook page is now sitting at 300 members. We'd an influx of members after Paul posted on the Helping Dumfries and Galloway page. Around 20 new people joined, many of whom hadn't heard of our wee charity or realised there was this support Network. Welcome to them!





Help from Rachel

The pandemic has brought out the best in many communities. It's wonderful to see the mutual support being offered in communities across our region. One such offer of support came from Rachel Lane, a charity advisor who has returned from London to support her Mum in Lochmaben. She's been offering the group her professional advice and support, which is very useful, as all on the committee are sufferers ourselves with no background in charities. She's suggested improvements to our website and clarity of message. We will hope to make these improvements when energies and pain levels allow.

In the meantime, she's offered to undertake a survey for us to help understand our members, their needs and also to identify if there's any skills out there which could potentially help support the Network and our aims.

Online Survey

This is a short online survey with around 20 questions, many of which are multiple choice. Please fill it in if you can. You can find it on our website, on Facebook, or via email or by [clicking here](#).

DAGCAS

Members are still having issues with the Benefit Agency and the usual, and extremely stressful problems around renewal of their benefits. Although busier than usual, with more advice around redundancy, and the debt issues caused by the pandemic, [Citizen's Advice/DAGCAS](#) continue their work by telephone. Please turn to them for advice and help in completing the forms and appealing decisions.

Emma Munro of DAGCAS spoke to us before lockdown and outlined the support available. Their Support 4 Life project sounded like it'd be particularly suited to our members' needs. In it they will help you identify any benefits you are entitled to, provide assistance in applying for them along with follow-up help should it go to appeal or tribunal, help identify any additional funding you may qualify for and help with other problems you may have, such as housing, debt, employment situations and more. An adviser will help you through the whole process. During normal times home visits could be arranged if need be, but obviously not for now.

You can access the [Support 4 Life service](#), along with the usual help and advice on 0300 303 4321.

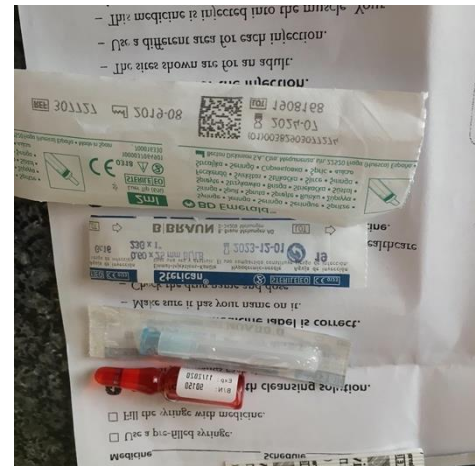
Feedback from Scottish Government Survey on "Lived Experience of ME"

Thanks to all who contributed to this online and through our meeting in March. The focus is off our condition for now, and I'd guess that work is distracted by the all-consuming pandemic, but it is to be hoped that when things begin to return to normal this survey and the need to reform care for ME/CFS patients is not forgotten.



My Experience of Self-Injecting

After about a week from having my B12 injection, my body works up quickly from subtle hints to full blown body slaps that I am about to deplete every last reserve. I am literally ready to drop from exhaustion and a combination of enhanced sensitivity, pain and discomfort. So being told I wasn't getting my injection due to the current situation with Coronavirus didn't go down well with me. I had naively thought the Facebook messages that GPs were still available for non Covid 19 patients, meant just that. It's not like I wanted something trivial, this was something essential to my health and well-being. After reading some Network posts on the subject of GP practices withholding B12 injections and doing my own research, I called my GP practice for a second time to explain how essential having my B12 injection was to me and that I was happy to self-administer it.



Long story short, after a telephone appointment with the nurse I was issued with a B12 ampule, 2 needles, a syringe, a sharps box and two pages of instructions. I'm not really sure you could call them instructions as they listed no exact method for administering a B12 injection. I had watched videos about self-administering in the past, but too long ago to remember them. I initially thought I would inject into my thigh but to be honest I am really sore in these areas. The YouTube video I watched, to offer myself some Dutch courage, showed the person being able to inject themselves in the arm. Mind set, I would inject in my left arm. I opened our first aid box and got a sterile pad and a plaster. Ray, my husband, had suggested I inject myself while lying on the floor in case I fainted. Instead, I took myself to the bathroom and even filmed myself since I knew I would have the same doubts had I needed to do this again. The thing I was most worried about was opening the ampule. I also wasn't sure about pinching the skin or flattening it out as either could make doing the injection more complicated on my own.

I don't suppose sitting on the toilet, with the seat down, while looking in a mirror and videoing myself for reference was the best idea for my first time. I washed my hands then used hand sanitiser, attached the needle to the syringe, opened the B12 ampule, drew up the solution, flicked the syringe to remove any air bubbles, sterilised my upper arm and made the injection at 90 degrees. Yes, I was very aware of sticking myself with a needle but it actually went in very easily and with no pain. I administered the B12 slowly and retracted the needle at the same angle. I sheathed the needle and popped it still attached to the syringe into the sharps box. I bled a little, but I normally do, so I put a plaster on. That's when I felt it. I normally feel something a bit weird so this sensation was to be expected and was fairly short lived.



Job done. I was pretty pleased with myself to the extent that I posted my endeavour on Facebook. Although I was nervous, I can honestly say it was fine and that I am happy to continue to self-inject my B12. This means 1 appointment available for another patient with the nurse instead of me.

Kim Jakobsen

**We asked our facebook members:
How is everyone coping with lockdown?**

I'm struggling with the isolation and also anxiety about cleaning everything down that comes in the house.

Although I have moments of panic and anxiety, my scalp psoriasis is clearing a little.

I do have days where I feel lonely or unwell, but I'm looking at the positives too xx

My anxiety has been really bad doctors upped my Sertraline to max dose of 200 I've not been the best hence not be joining zoom chats I'm starting to feel a bit more me now tho if you no what that means xx

I am enjoying not needing an excuse to stay at home. I am loving weekly face time catch ups with my family. Have really enjoyed learning to sew, making wash bags, pj's, scrubs and even a couple of face masks for myself. Glad to have been given the incentive to manage my own B12 injections. I am so grateful and thankful that my family are all well.

I'm now going downhill rapidly, which happens at this time of year when I'm exposed to the farm weed killers. I'd planned to be away to escape it - which if I time it right usually gives me a good spell through to August. That is frustrating me but I'm resigned to it and the likely lasting deterioration.

I just want to give the kids a big hug.

I'm loving the lockdown. I usually work part time as a school cleaner and come home after my shift exhausted and in pain. I worked one week after the schools closed to do a deep clean, then I phoned up work and said about me having ME/CFS and being at risk, they said that's me off for 12 weeks then. Happy days 😊. The pain in my hands, arms, shoulders etc has eased up a lot with not working. I'm keeping busy trying to get my youngest to do schoolwork and been busy making up orders for my wee wax melts business. I'm hoping one day to be able to do that properly and quit my cleaning job 😊

I'm happier. I feel safe and secure, hubby is at home so he can do loads for me and extra jobs. Just means I'm going to have separation anxiety when he goes back to work 😊 x

I really hope I don't need to go into shops, it's too much!!

I'm beginning to feel trapped now as I'm not being able to travel anywhere. I don't get out much but the 8 weeks not going anywhere at all is really getting to me now. I miss the open road and the views as well as the change in scenery. I've been affected also by everyone else around me being in a similar position i.e. mostly housebound if they're not an essential worker. Being mostly housebound with severe ME was somehow easier to bear knowing that life in general was carrying on as normal. This gave me comfort, and this has now gone.

Awareness Day Concerns Covid-19 Will Trigger ME

To tie in with Awareness Day we organised for a newspaper article in some of our local papers. The reporter covered our concerns for our regular healthcare, particularly the dropping of regular B12 injections; access to grocery delivery services; the concerns that people who develop Post Viral Fatigue Syndrome after Covid-19 won't have a pathway to diagnosis and care and won't receive advice about the importance of allowing their bodies time to recover. We also let people know about our online services.

To our surprise D&G Council lit their headquarters in purple for Fibromyalgia Awareness. This was done at the height of the lockdown so I'm afraid I didn't get to see it or get a photo. The news that they were doing this gathered a lot of interest online however and was useful in itself. Well done to the Council and to those who organised this.



STAYING HOME... chairman of the local ME network Craig Woods hosting an online meeting

ME group's covid concerns

SPENDING extended periods at home is not unusual for sufferers of myalgic encephalomyelitis (ME).

The chronic fatigue syndrome (CFS) is often brought on after a virus and, as the country prepares for week eight of Covid-19 lockdown, members of the local ME/CFS support network are preparing for a new wave of sufferers.

Their annual awareness day takes place on Tuesday and chairman of the local branch, Craig Woods, is taking the opportunity to let people know how the virus could trigger post-viral fatigue syndrome. He said: "There does not seem to be a pathway to diagnosis in this region for ME/CFS and there are no specialists for us to see."

"We are very worried that those suffering from continuing symptoms will get the wrong advice and told to 'push through' when they should be allowing their bodies time to recover."

"Many members, myself included, fell ill after a viral onset."

"We see that those that fight it hard do themselves a lot of harm and often don't recover, whereas those who treat their bodies more gently are much more likely to recover or be less badly affected."

During the pandemic lockdown

the network's meetings and social interactions have been held online - with video calls and a second Facebook page.

Craig added: "Our main Facebook page and the blog on our website are sharing the important information we need to know and we are supporting one another with advice and mental support."

Meanwhile, members have reported trouble accessing the regular services that they need. Craig explained: "The regular B12 injections seems to be a particular problem but patients are being empowered to inject themselves, taking the risk away from attending the surgery."

"Telephone appointments can often suit us better too."

Otherwise, sufferers struggle to access the online grocery deliveries that they used to often rely on because of the huge demand from the general population.

"We are also finding it fascinating how the world adapts to a lifestyle which has been forced upon us by ill health - it shows that more adaptations could have been made before now to adapt for the disabled and chronically ill."

Pain Association Zoom Meeting

We have been trying for a while to organise for someone from the Pain Association to attend one of our Midsteeple meetings. We hadn't managed to find a mutual time to suit, so when we went online it seemed like a good opportunity for our first invited guest. Phil Sizer joined us and talked about the course and the aims behind it. It is not aimed at any specific illness and is entirely from the Bio-Psycho-Social model – which it has to be said does have a bit of a troubled history in ME. Some of our members have also attended their courses (held regularly in Dumfries and Stranraer and free to attend with self-referral) and I have followed one online.

The consensus of our members who joined seemed to be that it could be of use, particularly for the newly ill, but also there were some elements in there which could be harmful for those newly ill and could potentially worsen their outcomes.

Acceptance and Adjustment Guidance for Those Newly Diagnosed with ME/CFS

Dr Purdie is undertaking a project to develop a guidance course with the above title for D&G NHS. This is intended to support those who are newly ill and to help them adjust to a life with ME and the unique challenges our symptoms presents. Some of it will be based on the Pain Association guidance but it will be tailored specifically for people with ME. Post Exertional Malaise, particularly, is not factored in to The Pain Association guidance. Dr Purdie has asked the Network to gather together some interested 'expert patients' to act as a reference group in creating this course. The consultation will probably start in August and will be online. Could those interested in taking part please email or message their interest?

If done well this has the potential to pass on the benefit of our difficult experiences in the early stages of the illness and help prevent newly ill people making mistakes and will give them the best chance of recovery. This is especially important now when there's the potential for a surge in numbers post-Covid.

Exciting New Research Project Announced

As I'm putting the finishing touches to the newsletter, a story has broken of a new £3.5m trial being funded by the UK. It is being led by Prof Chris Ponting (who I was impressed by when I met him in the Scottish Parliament) of the Medical Research Council Human Genetics Unit at the University of Edinburgh in collaboration with the UK ME/CFS Biobank at the London School of Hygiene & Tropical Medicine.



It will analyse DNA from the saliva of people with ME/CFS to see whether the disease is partly genetic, and if so, help pinpoint what causes it. The study should help us understand the disease and ultimately find treatments.

They need 20,000 people, healthy as well as those with ME/CFS, to give samples. If you're interested, please get in touch, so that when the study launches in early 2021, they can start reaching out to potential participants and collecting samples immediately. They need healthy people as well as ME/CFS sufferers. Register your interest at www.decode-me.org.uk.

People with ME/CFS are at the heart of the study, with a patient and a carer as co-investigators alongside the scientists and a steering group of people with the illness, carers and charities. The work is funded by the Medical Research Council and the National Institute for Health Research.

Editor's note: It really still shouldn't be happening but I've heard from a couple of members saying how difficult it is to spend time with their partners and family in lockdown because of their disbelief that fibromyalgia is a 'real' illness. I hope this article from the Phoenix Rising website helps to explain. [Click here](#) for the original article on the excellent [Health Rising](#) website.

Ten Ways to Prove That Fibromyalgia is a Real and Serious Disease

by [Cort Johnson](#) | Apr 12, 2020

#1. Very Painful!

The third myth that Medical News Today pointed out was that "the pain (in FM) is minimal and does not affect daily life".

Oh contraire. Studies indicate that fibromyalgia is actually one of the more painful diseases there are. A large North American study which contrasted the pain levels in juvenile FM patients with those of young people with other rheumatic diseases found it was no contest: pain levels were significantly higher, and functioning and well-being levels were **significantly lower** in the kids with FM.

One website that cites seven distinct kinds of pain found in FM indicates what a pain artist the disease is. It's not easy, after all, for a single disease to produce seven distinct kinds of pain, but if you really want to know about pain, you have to go to FM patients themselves. Check out some of their descriptions of pain:



- "blood vessels feel like they're on fire"
- "It feels as if someone is blowing up a balloon in my head and it's about to explode"
- "pain that's like fire ants are swarming through my veins and biting, along the way spreading their venom and pure burning inflammation"
- "I feel as if I have been thrown off the Empire State Building with resulting crushed bones and then had my entire body roasted by a blowtorch and then submerged in subarctic water"
- "someone spread finely crushed glass into all my muscles (and then I moved)"
- "it feels like an army of thugs is belting me continuously with baseball bats"
- "like little bugs are taking little tiny bites into my nerves and muscle fibres".

From "In Their Own Words: Chronic Fatigue Syndrome and Fibromyalgia Patients Describe Their Symptoms".

That sounds pretty real to me. It's just the beginning of the story, though.

#2. Central Sensitization Disorder Means Widespread Pain and Trouble

Fibromyalgia has been called the prototypical central sensitization disorder, but what does that mean? It turns out that it means a lot of trouble. The fact that major pain producing pathways in the nervous system have gone on hyper-alert means the pain for FM patients isn't confined to their hand or their arm or their leg – it's widespread. In fact, the 2010 criteria for FM require that people with FM experience widespread pain. Plus, the pain pathways in the spinal cords and brains of FM patients can become so hypersensitive to stimuli that even a touch, a bright light, or an innocuous odour can produce pain.

Unfortunately, it's not just pain that's widespread...



#3. Widespread Symptoms Mean Trouble Virtually Everywhere

Pain is the just beginning of the many issues that people with FM typically face. FM also produces high rates of fatigue and problems with sleep and cognition. While the physical manifestations of the disease outweigh the psychological ones, depression and anxiety may be present as well.

So, besides experiencing widespread pain, a typical person with FM feels sleep-deprived, fatigued,

experiences difficulty thinking and may be dealing with depression or anxiety. Still think FM is a nothing disease?

#4. Quality of Life Often Severely Impacted

Studies indicate that even by the standards of the medical profession, people with FM are having a tough time. A review of dozens of studies found that FM had a **similar or greater impact** on both the physical and mental health of people with FM, when compared to people with rheumatoid arthritis, osteoarthritis, osteoporosis, systemic lupus erythematosus, myofascial pain syndrome, primary Sjögren's syndrome, and others.

Another study found lower health-related quality of life scores in FM than in people with rheumatoid arthritis and spondyloarthritis, and a 2018 study found that fibromyalgia impacts a person's quality of life as severely as does multiple sclerosis. That paper stated: "FM is a disorder that 'in itself' can have a devastating impact on an individual's life."

If you haven't gotten by now that FM is a real and serious disease, I don't know what it's going to take, but there's more.

#5. Can Be Quite Disabling

It's difficult to understand how a "fake" disease could produce disability. A bit of fatigue, some discomfort, worry and anxiety – yes – but high rates of unemployment and/or disability? No.

Fibromyalgia does, though. A 325-person study found that over 50% of FM patients were either on sick leave or not working and that 23% had some degree of permanent work disability pension. In a study of the costs of chronic pain in the European Union, FM was found to produce the highest unemployment rate the most disability claims, and the most days absent from work of any pain condition. That's pretty bad, but it doesn't get any better. It turns out that FM is a challenging disease to treat as well.

#6. Not Easy To Treat

If a treatment works, you're going to keep taking it, right? The fact that three FDA-approved drugs for fibromyalgia exist might seem like a cause for celebration, but no one should think FM patients are on easy street. Far from it.

The truth is that the drugs approved for FM work well in only a relatively small subset of patients. A large year-long Israeli study (n=4,000 patients) found that less than 30% of people with FM filled their prescriptions twice and less than 10% were described as very adherent.

A study of juvenile FM patients over time found that youngsters' sense of well-being tended to remain the same over time or worsen, and concluded that "the symptoms of juvenile pediatric fibromyalgia syndrome remained persistent and disabling for many patients." In a survey, less than half of Canadian rheumatologists agreed that any of the current treatments for FM were effective.

While treatment programs can certainly help fibromyalgia patients, their outcomes tend to be modest. One recent review, "What You Can Do for Your Fibromyalgia Patient", advocated a "multifaceted, long-

term strategy” that was focused not on relieving pain but on simply making a person with FM more functional.

High rates of widespread pain, hypersensitivity to stimuli, fatigue, sleep and cognition problems, low quality of life, often disabling, difficult to treat: how much worse could it get? How about a tendency to come attached with other diseases as well?

#7. High Comorbid Disease Rate

It turns out that because FM likes to cluster with other diseases, people with FM often face other health problems as well. Check out the long (but probably not complete) list of other diseases that FM patients have an increased risk of picking up somewhere along the line.

They include: chronic fatigue syndrome, migraines and headaches, irritable bowel syndrome, temporomandibular joint syndrome, adult attention deficit hyperactivity disorder (ADHD), vulvodynia, interstitial cystitis.



#8. Fibromyalgia Makes Other Diseases Worse

Then there’s the flip side of the coin: people with chronic pain conditions have an increased risk of coming down with fibromyalgia. That’s called “secondary fibromyalgia” and when that happens – watch out!

One large study of people with rheumatic disorders found that having FM as well as another rheumatic disorders “had a remarkable impact on the severity of symptoms”. The impact was so large that the authors reported that FM essentially took over, with FM now becoming the patients’ main concern. The same generally held true for migraine. Migraine patients with FM had worse headaches, suffered from more disability, had more problems with depression, and the risk of suicide was increased compared than people with migraine only.

The economic impact appears to be equally large with the medical costs of rheumatoid arthritis patients with FM nearly double (@ \$19,000/year) that of RA patients without FM (@ \$10,000/year) – which brings up economics.

#9. High Economic Costs

Given that fibromyalgia is believed to affect from 4-10 million people in the U.S, the economic costs it imposes are, not surprisingly, large.

One review, “The Iceberg Nature of Fibromyalgia Burden: The Clinical and Economic Aspects”, reports that the clinical and economic costs of FM are comparable to such major and well-known diseases as diabetes, hypertension and osteoarthritis. It states that the mean annual **direct** medical costs of FM range from US \$2,274 to \$9,573 or more. That doesn’t include costs due to lost productivity and disability which could be 3-4x’s higher.

#10. Ignorant Doctors Make Everything Worse

We’ve established that FM is bear of a disease, but what makes everything worse, and what can make every visit to the doctor like tiptoeing through a minefield, are doctors who don’t get it, and don’t want to hear about it.

Good and caring doctors are certainly out there, but rheumatologists, in particular, are notorious for their aversion for treating fibromyalgia patients. A recent Canadian survey indicated that many doctors don’t even know how to diagnose FM.

"In general, the results are unsurprising and reflect the lack of knowledge about this common pain condition. Many patients who are referred to me with chronic pain problems are wrongly diagnosed with fibromyalgia or are wrongly diagnosed as not having fibromyalgia."

Another stated:

"I think most physicians are aware of fibromyalgia, although many still don't believe in it and communicate this [lack of belief] to their patients."

A survey of Canadian rheumatologists found that 30% believed FM was a psychosocial – not a medical – condition, and only 27% believed FM could get so bad as to stop someone from working. Despite the fact that FM falls under their specialty, half of them stated they would **refuse consultations** with FM patients. Given that most rheumatologists apparently threw the survey in the trash (42% response rate), this was probably a significant undercount.

Conclusion

By all markers – symptom severity, the multiple symptoms the disease produces, quality of life measures, disability, its many comorbid diseases, economic impact, etc. – fibromyalgia is clearly a real and serious disorder that has the ability to impact virtually every area of one's life. Many doctors, unfortunately, choose to ignore the evidence before them. It's not just doctors, however. Everyone – patients, doctors, researchers – would be helped by a better understanding of this disease. Unfortunately, the largest medical funder in the world, the National Institutes of Health, apparently doesn't believe FM is a serious disorder either: it spends about \$12 a year per patient in FM research – one of the lowest ratios of any disease.

ME Association Covid Advice

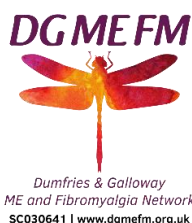
The ME Association has produced a series of valuable resources including up to date advice, leaflets and a 'To Whom It May Concern' letter helping you to state your vulnerable status.

Along with all the usual advice and resources they are available on their website or by phoning their ME Connect advice line on 0344 576 5326. The line is open every day of the week from 10am-12pm, 2pm-4pm and 7pm-9pm

Help to Run the Network

If you or someone you know have any contribution you could make in terms of skills, expertise or time that you could make towards helping run the Network we'd be very pleased to hear from you!

If there's something you'd like to see in the next newsletter, or you feel able to write something for us, please do so and share by the end of August. Member contributions are very valued.



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